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*Jack Hadley* *May 1, 1996*  
PI - Signature Date

# **Cost Effectiveness of Alternative Treatments for Local Breast Cancer in the Elderly**

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Appendix 1: Preliminary Patient Interview Instrument

Appendix 2: Preliminary Physician Interview Instrument



## **I. INTRODUCTION**

### **Nature of the Problem and Background**

In 1994, 183,000 women developed breast cancer and 47,000 women died of the disease. Forty-four percent of the new cases and 56 percent of the deaths occurred among the 13 percent of the female population which was 65 or older. Thus, more than 80,000 elderly women are diagnosed with breast cancer each year and, based on increased use of screening examinations, upwards of 70 percent of these women should be diagnosed in local stages (Tabar et al., 1985).

As a consequence of this high burden of disease, the elderly incur a disproportionate share of the \$35 billion in annual direct medical costs of cancer in the U.S. In addition, the cost of medical care to the Medicare program for breast cancer survivors is substantial. On average, breast cancer survivors live an additional 11.2 years and incur almost \$54,000 in Medicare costs (Riley et al., 1995). Despite the enormous resources expended on cancer care, little is known about the financial impact of alternative cancer therapies.

Randomized clinical trials of breast cancer therapies conducted in the 1980s have demonstrated that breast conserving surgery (BCS) with radiation therapy (RT) yields equal survival to modified radical mastectomy (MRM) (Bader et al., 1987; Fisher et al., 1985; Fisher et al., 1989). However, few elderly women were included in those trials. Further follow-up of women in the trials indicates that survival rates for local stage disease continue to be equivalent for both treatment modalities, whether or not BCS is accompanied by RT (Early Breast Cancer Cooperative Group, 1995; Fisher et al., 1995). However, local recurrence rates are 30% higher in women who did not receive RT in conjunction with BCS compared to BCS with RT. Although age was not considered a contraindication to either treatment modality (Steinfeld et al., 1989; Balducci et al., 1991), there has been very little direct analysis of the effects of alternative treatment choices on survival or recurrence in the elderly.

In spite of the evidence from clinical trials, the use of BCS by elderly patients varies greatly and appears to be under-used. Estimates from the late 1980s indicate that only 3.5% to 21% of elderly women received BCS; fewer than half of these women received RT (Chu et al., 1987; Yancik et al., 1989; Silliman et al., 1989; Lazovich et al., 1991; Bergman et al., 1991; Farrow et al., 1992; Nattinger et al., 1992; Newcomb and Carbone, 1993). Numerous other studies have documented additional age-related variations in breast cancer treatment (Greenfield et al., 1987; Samet et al., 1986; Silliman et al., 1989; Chu et al., 1987; Lazovich et al., 1991; Bergman, et al., 1991; Farrow et al., 1992), including less aggressive use of intravenous adjuvant chemotherapies (Newcomb and Carbone, 1993; Silliman et al., 1989; Allen et al., 1986; Chu et al., 1987), despite similar rates of toxicities seen in younger patients (Begg and Carbone, 1992), and fewer consultations with medical or radiation ecologists in elderly compared to non-elderly women (Newcomb and Carbone, 1993).

The few cost-effectiveness analyses that have examined treatment of local breast cancer have focused on younger women (Smith and Hillner, 1993), and/or have used data from RCTs (Smith and Hillner, 1993; Hillner and Smith, 1991; Verhoef et al., 1991). The efficacy of treatment and cost observed under RCT conditions are not likely to replicate those expected in actual clinical practice, where the populations are more heterogeneous and treatments less intense (Eisenberg, 1989; Drummond and Davies, 1991; Smith, Hillner, and Desch, 1993). This concern may be particularly germane when addressing the elderly, because of their substantial diversity in health, functional status, and social support. In addition, few breast cancer trials have included elderly women, especially those aged 75 or more. Munoz and colleagues, using 1983-1984 charge data for a case series of 79 women treated in one hospital found BCS and RT to be 37% more expensive than MRM; however, surgeons' fees were 55% higher for the MRM than for the more conservative surgery (1986).

## **Goals and Methods of Approach**

The goal of this project is to conduct cost-effectiveness analyses of three treatment modalities for breast cancer (MRM, BCS with RT, and BCS without RT) in elderly women with local disease. Benefits will be based on survival and quality of life measured annually up to five years post-treatment. Costs will be measured from the social perspective and will be based primarily on the direct costs of all medical care. Secondary analyses will consider various substrata of women, based on age (67-75, older than 75), initial health state (derived from comorbidities at time of diagnosis and prior medical care use), place of residence (urban or rural), marital status and living arrangement at time of treatment (alone, with spouse, with others), and hospital type (cancer center, other teaching hospital, nonteaching)

Actual practice may deviate from recommended guidelines for several reasons: elderly women's poorer health generally, preferences and quality of life assessments, fewer social supports, diminished socioeconomic status, transportation difficulties, and poorer access to high-volume breast cancer surgeons and radiation therapy centers. Prior research, which has typically examined only one or two of these elements and has not focused primarily on elderly patients, provides few insights on these questions. By conducting cost-effectiveness analyses that take these factors into account, the proposed project will assess whether elderly women, generally or in particular circumstances, are receiving sub-optimal patterns of care. If they are, our analyses of treatment choice determinants and of the relationship between treatments and outcomes will generate recommendations for policy changes to alter treatment patterns, as well as to provide information for developing clinical guidelines regarding preferred treatment choices under a variety of patient and environmental circumstances.

Data will be collected by a telephone survey of a nationally representative sample of 2,500 Medicare beneficiaries who were treated for local breast cancer between 1991 and 1995. All

interviews will be conducted in 1996 to obtain cross-sectional data on women who are 1-5 years post-treatment. Medical care use will come from the Medicare National Claims History file for all respondents, nonrespondents, and approximately 700 decedents. (Cost data for decedents will be used in calculating cost-effectiveness ratios.) The sample will be drawn from the case loads of a random sample of 500 surgeons who performed breast surgery between 1991-1995. Surgeons will be surveyed by mail (with telephone follow-up) to obtain information on sample patients' disease stage. The relationship between treatment and outcomes will be estimated using an approach to correct for bias due to the observational nature of the data.

Cost-effectiveness analysis will be used to combine the costs and outcomes of treatment over the five year evaluation period. Cost-effectiveness ratios will be constructed based upon the formula  $CER_t = \Sigma Costs_t / \Sigma QALYs_t$  where  $t$ =treatment modality (MRM, BCS w/RT, BCS w/o RT). Costs are calculated from Medicare claims and QALYs are calculated from five-year survival curves for each of the three treatment outcomes and patient preference assessments (based upon adjusted patient EuroQol® scores) at approximately years 1, 2, 3, 4, and 5. Preference assessments for time periods between measurements will be interpolated linearly, or extrapolated on a patient age-adjusted basis. We shall then divide the treatment survival curve for each of the three therapies into five 12 month segments. We will multiply the average patient months of survival for each portion of the survival curve by the average preference weight for that time period to develop a measure of the total preference-adjusted survival months for each segment of the survival curve. The number of QALYs for each of the three therapies will be taken as the discounted sum of the preference-adjusted survival months of the five curve segments. This method will account for survivor bias in responses to the preferences instruments because we will include all patients in the calculations, with patients who die having a preference weight of 0 from the date of death to the end of the observation period.

## **II. PROGRESS DURING YEAR ONE**

### **Complementary with a Related Research Project**

Shortly after beginning work on this project, Georgetown University received a grant from the Agency for Health Care Policy and Research (AHCPR) of the U. S. Dept. Of Health and Human Services to conduct a five-year study titled "Care, Costs, and Outcomes of Local Breast Cancer in Elderly Women." As suggested by the title, the AHCPR grant complements this project in a number of ways. Like this project, one of its goals is to conduct a cost-effectiveness analysis of breast cancer treatment options in elderly women with early stage disease. In addition, the second major goal of the AHCPR grant is to estimate a comprehensive model of the treatment choice process.

In order to implement these two goals, the AHCPR grant is pursuing a dual data collection strategy. The analysis of treatment choice will be based on primary data collected prospectively from a cohort of approximately 800 newly diagnosed cases of early stage breast cancer in elderly women. Women for this cohort are being accrued in 40 hospitals in four geographically diverse sites: greater Boston, Rochester and Buffalo, Washington D.C., and Texas. In-person baseline interviews are being conducted 10 to 14 weeks post-treatment; medical records are being abstracted; and women's surgeons are being administered a mail survey instrument to obtain information on treatment propensities in hypothetical cases and actual treatment patterns.

The baseline in-person interviews are collecting detailed information on the treatment choice process, women's socio-economic situations, and initial health states. The cohort of 800 women will be interviewed annually by telephone at one and two years post-treatment. The follow-up interviews will obtain information on overall quality of life and several dimensions of specific health and functional status, as well as major changes in socio-economic status or living arrangements.

The second element of the AHCPR grant's data collection strategy is national surveys of random samples of elderly women treated for breast cancer and their surgeons at three, four, and five years post-treatment. Surgeons will be surveyed by a combination of mail and telephone, and women will be interviewed by telephone. This phase of the AHCPR project overlaps substantially with the national surveys planned for this grant. Moreover, both projects will use secondary data from Medicare's National Claims History File to develop the measures of medical care costs, baseline comorbidities, and pretreatment medical care use and medical conditions (if any).

Given the **complementary** between the two research projects, we are in the process of requesting a change in the scope of work for the DoA grant that we believe will improve substantially the statistical power of the planned work. As will be described in greater detail below, rather than conducting surveys of 500 women per year at one through five years post-treatment, as was originally proposed for this grant, we believe that it will be far more advantageous to combine the data collection activities of the two projects. Specifically, we propose to use the primary data cohort of 800 women per year supported by the AHCPR grant to obtain information for one and two years post-treatment. The total sample of 2,500 proposed for this project will be reallocated to three, four, and five years post-treatment, which will supplement the national surveys planned for the AHCPR project.

The final size of the AHCPR samples is somewhat uncertain at the moment because of possible reductions in AHCPR's budget. At a minimum, however, the number of patients available for the cost-effectiveness analyses proposed for this grant will increase from 500 per year to 800 per year for one and two years post-treatment, and 833 women per year for three, four, and five years post-treatment. Thus, the overall sample size will be increased by 64%, from 2,500 women to 4,100. This increase in sample will provide greater statistical power for hypotheses testing, and thus more precision in the calculations planned for sub-groups of patients.

Given the potential advantages of combining the two projects, we have temporarily suspended work on the DoA grant pending the review of our request to modify the scope of work. Part of our request for a modified scope of work includes a one year, no cost extension of the period of performance so that the post-treatment years in the two projects can be aligned. Although this will delay completion of the analysis by one year, it will also permit us to calculate the cost-effectiveness ratios with data for more recent years. Given that treatment patterns for early stage breast cancer appear to be very dynamic, the more recent data will provide more accurate information for policy makers and clinicians.

### **Work Conducted During Year One**

Work conducted during the first year focused on the development of the survey instruments and sampling strategies, which would be the same whether or not the two surveys are combined. In particular, the patient survey instrument, which will be approximately 20 minutes long and administered by telephone, will be drawn from the baseline in-person patient interview, which is approximately 60 minutes long. Analysis of preliminary data from the in-person interviews, which will be undertaken as part of the AHCPR grant, will enable us to identify the most important variables and questions for inclusion in the national patient survey. Thus, considerable effort went into the development of questions that can be administered by telephone as well as in person.

Appendix 1 is a copy of the in-person patient interview *developed for the AHCPR PORT project. The telephone survey instrument, which will be used for the national patient survey supported by the DoA grant, will be derived from this instrument.*

The analysis of the preliminary survey data will also help guide decisions about the most important variables to include. For example, there are several approaches to measuring baseline and immediate post-treatment health status. Preliminary analysis will indicate how closely

correlated the alternative measures are and how much they vary across respondents. This information will be very helpful in choosing questions for the telephone instrument, which will measure health and functional status at three to five years post-treatment. As another example of the interaction between the two projects, preliminary analysis of the baseline data will indicate which socioeconomic variables appear to be strongly correlated with either treatment choice or health outcome and, therefore, should be given a high priority for inclusion in the national telephone survey instrument.

The second major product of the first year is the *draft physician survey instrument*. As with the patient survey instrument, the current draft of the physician survey instrument (attached as Appendix 2) is the one being used to collect information from surgeons whose patients are part of the AHCPR PORT longitudinal cohort. The final survey instrument will be derived from this one. In addition, a new page will be developed to ask physicians about the stage of disease for their specific patients who are selected as part of the national patient survey.

By working collaboratively with the AHCPR breast cancer PORT, we were able to take advantage of the considerable amount of clinical expertise available to that project. That led to the development of three hypothetical case scenarios designed to elicit physicians' propensities with regard to the three treatment choices under investigation. By design, the scenarios are ambiguous, in the sense that there are no clear-cut indications that should favor selection of one treatment choice over the others. This instrument also provides potentially useful information about physicians' actual practice patterns in treating women with breast cancer, as well as data on the importance they attach to various factors in making decisions about treatment choice.

The last activity of the first year was the development of the strategy for drawing the samples of physicians and their patients. We are currently specifying the data request for submission to the Health Care Financing Administration, which will provide data on the universe



of breast cancer patients and their surgeons. The sampling strategy, which will be refined in the second year, calls for stratifying surgeons by their volume of elderly breast cancer patients, drawing random samples of surgeons from each strata, and, for surgeons with large volumes of patients, drawing random samples of their patients.

*Table 1 delineates all of the activities undertaken during the first years of both this grant and the AHCPR grant. The sources of support for each task are indicated in the adjoining columns. Not surprisingly, the majority of the total work was supported by the AHCPR grant because of its broader scope and the necessity of initiating the longitudinal data collection before the national surveys. Combining resources from the two grants in the activities that were jointly supported enabled an expansion of the faculty and expertise brought to bear in developing the survey instruments, and a more thorough consideration of content and structural issues than would have been possible if this grant's work were conducted independently and separately from the AHCPR grant.*

## **CONCLUSIONS**

Substantial progress was made during year one in the development of the survey instruments, survey methods, and the specification of data sources. Although work on this project has been suspended temporarily, integrating this project with our highly complementary project from AHCPR should substantially improve the value of the final product: a series of cost-effectiveness analyses of alternative treatments for breast cancer in elderly women.

If our request for a modification to the scope of work is approved, we will proceed to integrate fully the planning and execution of the national surveys of breast cancer patients and their surgeons. The samples will be drawn from women who were treated in 1992 through 1994. Surgeons will be surveyed in late 1996/early 1997. The patient survey will be conducted in 1997,

so that the women interviewed will be three, four, or five years post-treatment. The cost-effectiveness analyses will be conducted during the last year of the project.

Table 1

*Activities Conducted During the  
First Year of the DoA and AHCPR Breast Cancer Grants*

	Source of Support	
	DoA	AHCPR
1. Specify criteria for identifying and accruing patients in the longitudinal cohort.		✓
2. Specify criteria for identifying and accruing surgeons in cohort sites.		✓
3. Develop patient survey instruments.		
a. Review existing instruments and develop new content	✓	✓
b. Conduct focus groups and cognitive lab testing		✓
c. Conduct pre-test		✓
4. Develop medical records abstracting form and protocol.		✓
5. Develop surgeon survey instrument		✓
a. Review existing surveys and identifying relevant items.	✓	✓
b. Construct "toss-up" case scenarios	✓	✓
6. Develop protocol for data collection management		✓
7. Develop IRB submissions for longitudinal cohort		✓
8. Conduct preliminary assessment of secondary data needs		✓
a. Draft initial request for HCFA data	✓	✓
b. Identify other potential sources of secondary data	✓	✓
9. Train project coordinators, data abstractors, and interviewers.		✓

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## **Appendix 1**

### **Patient In-Person Interview Instrument Developed for AHCPR Grant No. HS0835<sup>1</sup>**

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<sup>1</sup>The National Patient Survey Instrument will be derived from this instrument following analysis of preliminary data.

Pat ID: \_\_\_\_\_

Int ID: \_\_\_\_\_

Site: \_\_\_\_\_

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Breast Cancer

***O***UTCOMES AND  
***P***REFERENCES FOR  
***T***REATMENT  
***I***N  
***O***LDER WOMEN  
***N***ATIONWIDE  
***S***URVEY

**Patient Baseline Interview Questionnaire**



INTRODUCTION - Hello. My name is (\_\_\_\_\_), and I'm working with Drs. (\_\_\_\_\_) from (\_\_\_\_\_) on the OPTIONS study of patients with breast cancer. I'd like to give you some information and ask you some questions. To make sure you have all the correct information, I'm going to read you a few sentences about the study.

- The study I'm asking you to participate in will provide very important information to women, their doctors, and the public concerning how decisions are made in the care of older women with breast cancer.
- Your participation is very important for the success of this research. Your name will not be used; you will be identified by number only.
- The doctor who did your surgery is aware that you are being asked to participate.
- I will be asking questions about your current health and about the treatment you had for your breast cancer.
- You are free to decide not to be involved at all or you may stop at any time. You are free to refuse to answer any question or group of questions. Your future care will not be affected by whether or not you participate in this study.
- I would like you to answer some questions today that will take between 45 and 60 minutes.
- You will be contacted by the OPTIONS project by telephone 9 and 21 months from now. The times will be scheduled at your convenience and won't take longer than half an hour on the telephone.
- We will send you a newsletter with information about the study periodically over the next 2 years.
- Do you have any questions about the study?
- Will you participate? May I begin?

Yes \_\_\_\_\_

No \_\_\_\_\_ (CONTINUE WITH REFUSAL QUESTIONS  
PAGE 2)

ACTIVE CONSENT? Yes \_\_\_\_\_ (CONTINUE BELOW OR USE  
INSTITUTIONAL CONSENT FORM)

No \_\_\_\_\_ (GO TO PAGE 5)

I understand the information above and agree to participate:

\_\_\_\_\_  
Patient Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Interviewer Name

\_\_\_\_\_  
Date

GO TO PAGE 5

REFUSAL QUESTIONS

(ONLY FOR WOMEN REFUSING TO PARTICIPATE)

I understand that you do not wish to participate in this study. May I, however, ask you to answer a few quick questions for me? Your cooperation would be deeply appreciated.

R1. Why don't you want to be in this study? (RECORD ANSWER)

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---

---

R2. What is your race or ethnic background? (RECORD ANSWER)

---

Black (non-Hispanic) ..... 1  
White (non-Hispanic) ..... 2  
Hispanic (Puerto Rican, Cuban, Mexican, Chicano,  
Other Latin American, or Other Spanish) ..... 3  
Aleut, Eskimo, or American Indian ..... 4  
Asian / Pacific Islander ..... 5  
DON'T KNOW/UNSURE ..... 99

R3. What is the highest grade or level of schooling you completed? (CODE ONLY ONE;  
CODE HIGHEST LEVEL OF EDUCATION OBTAINED)

- No formal schooling ..... 00
- Elementary:
- 1st grade ..... 01
- 2nd grade ..... 02
- 3rd grade ..... 03
- 4th grade ..... 04
- 5th grade ..... 05
- 6th grade ..... 06
- 7th grade ..... 07
- 8th grade ..... 08
- High School:
- 9th grade ..... 09
- 10th grade ..... 10
- 11th grade ..... 11
- 12th grade or GED ..... 12
- College and Graduate/professional School:
- 1 year ..... 13
- 2 years ..... 14
- 3 years ..... 15
- 4 years ..... 16
- 5 years ..... 17
- 6 or more years ..... 18
- Post-High School Training Other Than College (e.g.  
Vocational or Technical Training) ..... 66
- OTHER (SPECIFY) \_\_\_\_\_ 77
- REFUSAL ..... 88
- DON'T KNOW/UNSURE ..... 99

R4. Are you... (PROMPT BY READING CHOICES IF NECESSARY; IF SINGLE, PROBE  
FOR OTHER CHOICES)

- Married? ..... 1
- Divorced? ..... 2
- Separated? ..... 3
- Widowed? ..... 4
- Single (never married)? ..... 5
- OTHER (SPECIFY) \_\_\_\_\_ 77
- DON'T KNOW/UNSURE ..... 99

R5. Do you have...

	Yes	No	Don't know
R5a. Medicare that covers doctors (that you pay for monthly)?	1	2	99
R5b. Medicaid?	1	2	99
R5c. Insurance that picks up what Medicare doesn't pay?	1	2	99

R5d. Do you have any insurance or are you part of a plan that covers prescription drugs?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

CONTINUE TO PAGE 5

Let me verify some information. Your name and other confidential information on this page will be kept in the research office, separate from your answers.

1. Patient's name

\_\_\_\_\_  
Last name

\_\_\_\_\_  
First name

\_\_\_\_\_  
M.I.

2. Patient's address

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. Date of birth

\_\_\_\_/\_\_\_\_/\_\_\_\_ (MM/DD/YY)

4. Social security number

\_\_\_\_-\_\_\_\_-\_\_\_\_

5. Index surgeon's name

\_\_\_\_\_

6. Medicare number

\_\_\_\_\_

AUTHORIZATION FOR RELEASE OF INFORMATION

Patient Name \_\_\_\_\_

Date of Birth

---

Address

City, State, Zip

Telephone Number

Medical Record #

Social Security #

I hereby authorize \_\_\_\_\_ at: \_\_\_\_\_ to  
 \_\_\_\_\_ Doctor or Hospital \_\_\_\_\_ Address  
 release information for research purposes from my medical record concerning my *breast cancer diagnosis and  
 treatment* to the OPTIONS Office:

Receiver Name \_\_\_\_\_

Address

City, State, Zip

Type of Service

Type of Record

---

Date \_\_\_\_\_

**This will release \_\_\_\_\_ from all liability that may arise as a result of compliance**  
**with my request.**  
**Doctor or Hospital**

Patient Name \_\_\_\_\_

Date \_\_\_\_\_

Witness \_\_\_\_\_

---

Date \_\_\_\_\_

<b>INTERVIEWER WORKSHEET</b>
------------------------------

1. From the time you first thought something was wrong with your breast until now, what happened? RECORD EACH PROCEDURE IN CHRONOLOGICAL ORDER

Procedure	Date	Place
1a. Index mammogram		
1b.		
1c.		
1d.		
1e.		
1f.		

2. Surgery Date:

\_\_\_\_/\_\_\_\_/\_\_\_\_ = SDATE

3. Diagnosis Date:

\_\_\_\_/\_\_\_\_/\_\_\_\_ = DDATE

4. 2 Months Prior to Diagnosis Date:

\_\_\_\_/\_\_\_\_/\_\_\_\_ = PDATE

5. Number of places in question #2:

\_\_\_\_ Places

**NOTE TO INTERVIEWER:**

- FILL OUT RECORDS RELEASES FOR **EACH PLACE** WHERE A PROCEDURE TOOK PLACE.
- PATIENT WILL SIGN TWO COPIES OF THE RECORDS RELEASE FOR EACH PLACE.
- LEAVE ONE COPY OF EACH RECORDS RELEASE WITH PATIENT.

Time interview began: \_\_\_\_\_:\_\_\_\_\_ AM/PM

Mode of interview:

In-person interview ..... 1  
Telephone interview ..... 2

Place of interview:

Home ..... 1  
Hospital ..... 2  
OTHER (SPECIFY) \_\_\_\_\_ 77

## Section I — SOCIO-DEMOGRAPHICS

INTRODUCTION: First, I would like to ask you some questions about yourself.

1. What is your birth date?

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (MM/DD/YY)

2. Are you currently married, divorced, separated, widowed, or never been married?

Married ..... 1  
Divorced ..... 2  
Separated ..... 3  
Widowed ..... 4  
Single (never married) ..... 5  
OTHER (SPECIFY) \_\_\_\_\_ 77  
DON'T KNOW/UNSURE ..... 99

3. What is your current living situation? Do you live... (READ CHOICES)

By yourself? ..... 1 (SKIP TO 4)  
With others? ..... 2



3a. Who lives with you? (PROMPT BY READING IF NECESSARY--CHECK ALL THAT APPLY)

Spouse or partner, with children ..... 1  
Spouse or partner, without children ..... 2  
Children ..... 3  
Roommates ..... 4  
Paid home health aide/nurse ..... 5  
Other family members ..... 6  
OTHER (SPECIFY) \_\_\_\_\_ 77

4. What is your zip code?

\_\_\_\_\_

5. Do you own or rent your home?

Own house ..... 1 (SKIP TO 6)  
Own condo or co-op ..... 2 (SKIP TO 6)  
Rent house ..... 3  
Rent apartment ..... 4  
Live with relative who owns ..... 5  
Live with relative who rents ..... 6  
Homeless ..... 7  
OTHER (SPECIFY) \_\_\_\_\_ 77  
REFUSAL ..... 88  
DON'T KNOW/UNSURE ..... 99

5a. Have you *ever* owned your *own* house or apartment?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

6. What is the highest grade or level of schooling you have completed?

No formal schooling .....	00
Elementary:	
1st grade .....	01
2nd grade .....	02
3rd grade .....	03
4th grade .....	04
5th grade .....	05
6th grade .....	06
7th grade .....	07
8th grade .....	08
High School:	
9th grade .....	09
10th grade .....	10
11th grade .....	11
12th grade or GED .....	12
College and Graduate/professional School:	
1 year .....	13
2 years .....	14
3 years .....	15
4 years .....	16
5 years .....	17
6 or more years .....	18
Post-High School Training Other Than College (e.g. Vocational or Technical Training) .....	66
OTHER (SPECIFY) _____	77
REFUSAL .....	88
DON'T KNOW/UNSURE .....	99

7.<sup>NHIS</sup> What is your race or ethnic background, for instance Black, White, Hispanic, Asian?

Specify \_\_\_\_\_ (THEN CODE)

Black (non-Hispanic) .....	1
White (non-Hispanic) .....	2
Hispanic (Puerto Rican, Cuban, Mexican, Chicano, Other Latin American, or Other Spanish) .....	3
Aleut, Eskimo, or American Indian .....	4
Asian / Pacific Islander .....	5
DON'T KNOW/UNSURE .....	99

8. Before your diagnosis in (DDATE), were you working for pay?

Yes ..... 1  
No ..... 2 (SKIP TO 8b)  
REFUSAL ..... 88 (SKIP TO 8b)  
DON'T KNOW/UNSURE ..... 99 (SKIP TO 8b)

8a. Were you working full or part time?

Full time ..... 1 (SKIP TO 9)  
Part time ..... 2 (SKIP TO 9)  
DON'T KNOW/UNSURE ..... 99 (SKIP TO 9)

8b. Which of the following best describes you then? Were you... (READ CHOICES)

A homemaker? ..... 1  
Unemployed? ..... 2  
Retired? ..... 3  
Disabled and too ill to work? ..... 4  
OTHER (SPECIFY) \_\_\_\_\_ 77  
REFUSAL ..... 88  
DON'T KNOW/UNSURE ..... 99

9. About how much money do you have coming in each month (from jobs, retirement plans, social security, and/or social services) for you (and your spouse)? I'll read the categories...(SHOW CARD JJ)

A. Less than \$500 ..... 1  
B. \$500 to \$999 ..... 2  
C. \$1,000 to \$1,999 ..... 3  
D. \$2,000 to \$2,999 ..... 4  
E. \$3,000 to \$3,999 ..... 5  
F. \$4,000 or more ..... 6  
REFUSED ..... 88  
DON'T KNOW/UNSURE ..... 99

These next questions are about your health insurance coverage.

10. Are you enrolled in an HMO?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

10a. What is the name of your plan?

\_\_\_\_\_

11. Do you have...

	Yes	No	Don't know
11a. Medicare that covers doctors (that you pay for monthly)?	1	2	99
11b. Medicaid?	1	2	99
11c. A plan that picks up what Medicare doesn't pay?	1	2	99

11d. Do you have any insurance or a plan that covers all or part of prescription drugs?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

12. Last month, how much money did you spend on medications and doctor's bills out of your own pocket? (PROBE: Will Medicare or any other insurance cover (reimburse you for) any of those bills? DEDUCT FROM TOTAL)

\$\_\_\_\_\_ Dollars (CODE UNSURE AS 999)

## Section II — GENERAL HEALTH AND MEDICAL CARE

INTRODUCTION: Now I'd like to ask about your health care.

1. I'm going to read you some things about health care that patients tell us are important to them. Please tell me if each issue is extremely important, somewhat important, neither important nor unimportant, somewhat unimportant or not important at all. (SHOW CARD A)

Factor	Extremely important	Somewhat important	Neither important nor unimportant	Somewhat unimportant	Not important at all
1a. Having most of your doctor and hospital bills paid for by your insurance (small copayments or deductibles).	1	2	3	4	5
1b. Being able to be seen by a specialist within 2 weeks, if you are referred by your regular doctor.	1	2	3	4	5
1c. Not having bills to send in when you go to the doctor.	1	2	3	4	5

2. Do you have a regular doctor?

Yes ..... 1  
No ..... 2 (SKIP TO 3)

- 2a.<sup>NHS</sup> How long have you been seeing this doctor?

\_\_\_\_\_ Years      \_\_\_\_\_ Months (CODE UNSURE AS 99,99)

2b. What kind of doctor (or clinic) is this?

GP/family practice ..... 1  
Internist/specialist ..... 2  
Geriatrician ..... 3  
Internist-general ..... 4  
Surgeon ..... 5  
OB/GYN ..... 6  
OTHER (SPECIFY) \_\_\_\_\_ 77  
DON'T KNOW/UNSURE ..... 99

Now I'd like to ask you about specific health conditions or problems that you might ever have had.<sup>1</sup> These questions refer to a time 2 months before your diagnosis, in (ENTER 2 MONTH PRIOR DATE: \_\_\_\_/\_\_\_\_) (PMONTH).

3.<sup>SG</sup> Before (PMONTH), had you *ever* been told by a doctor that you had any of the following problems with your breathing?

IF YES ASK: Did you take prescription medicine for this condition?

Condition	Condition			Prescription medicine		
	Yes	No	Don't know	Yes	No	Don't know
3a1. Emphysema?	1	2	99			
3a2. (IF YES ON 3a1)				1	2	99
3b1. Chronic bronchitis?	1	2	99			
3b2. (IF YES ON 3b1)				1	2	99
3c1. Asthma?	1	2	99			
3c2. (IF YES ON 3c1)				1	2	99
3d1. Anything else regarding breathing? (SPECIFY) _____	1	2	99			
3d2. (IF YES ON 3d1)				1	2	99

<sup>1</sup>Source for questions 3-5 Dr. S. Greenfield;

- 4.<sup>SG</sup> Before (PMONTH) had you *ever* been told by a doctor that you had any of the following problems related to your heart circulation?

IF YES ASK: Did you take prescription medicine for this condition?

Condition	Condition			Prescription medication		
	Yes	No	Don't know	Yes	No	Don't know
4a1. A heart attack?	1	2	99			
4a2. (IF YES ON 4a1)				1	2	99
4b1. Congestive heart failure?	1	2	99			
4b2. (IF YES ON 4b1)				1	2	99
4c1. High cholesterol?	1	2	99			
4c2. (IF YES ON 4c1)				1	2	99
4d1. Angina?	1	2	99			
4d2. (IF YES ON 4d1)				1	2	99
4e1. High blood pressure?	1	2	99			
4e2. (IF YES ON 4e1)				1	2	99
4f1. Other? (SPECIFY) _____	1	2	99			
4f2. (IF YES ON 4f1)				1	2	99

5.<sup>SG</sup> Before (PMONTH) had you ever been told by a doctor that you had any of the following heart problems?

IF YES ASK: Did you take prescription medicine for this condition?

Condition	Condition			Prescription medication		
	Yes	No	Don't know	Yes	No	Don't know
5a1. Stroke (Transient Ischemic Attack or small stroke that comes and goes within 24 hours)?	1	2	99			
5a2. (IF YES ON 5a1)				1	2	99
5b1. Epilepsy or seizure disorder?	1	2	99			
5b2. (IF YES ON 5b1)				1	2	99
5c1. Parkinson's disease?	1	2	99			
5c2. (IF YES ON 5c1)				1	2	99
5d1. Diabetes or high sugar?	1	2	99			
5d2. (IF YES ON 5d1)				1	2	99
5e1. Thyroid problems, either underactive or overactive?	1	2	99			
5e2. (IF YES ON 5e1)				1	2	99
5f1. Other? (SPECIFY) _____	1	2	99			
5f2. (IF YES ON 5f1)				1	2	99

6.<sup>KS</sup> Before (PMONTH) how many different types of *prescription* medicine, pills, and/or shots did you take a day (include all of your medical conditions)?

\_\_\_\_\_ Number (CODE 99 FOR UNSURE)

[INTERVIEWER: CHECK PREVIOUS QUESTIONS FOR OTHER MEDICATIONS]



7.<sup>KS</sup> Before (PMONTH) how many different *types* of non-prescription medicine and/or pills did you take a day?

\_\_\_\_\_ Number (CODE 99 FOR UNSURE)

8.<sup>SG</sup> Before (PMONTH) did you have any... (SHOW CARD B)

Symptom	More than once a week	Almost every week	Once or twice only	Never
8a. Chest pain or pressure when you exercise?	1	2	3	4
8b. Chest pain or pressure when resting?	1	2	3	4
8c. Ankles or legs that swell as the day goes on?	1	2	3	4

9.<sup>SG</sup> During (PMONTH), did you feel short of breath... (SHOW CARD C) (CIRCLE ONE FOR EACH ITEM)

Activity	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9a. When lying down flat?	1	2	3	4	5	6
9b. When sitting, resting?	1	2	3	4	5	6
9c. When walking less than one block?	1	2	3	4	5	6
9d. When climbing one flight of stairs?	1	2	3	4	5	6
9e. When climbing several flights of stairs?	1	2	3	4	5	6

### Section III — HEALTH STATUS<sup>1</sup>

The next questions ask about your health *two months prior* to your initial diagnosis or in \_\_\_\_/\_\_\_\_ (PMONTH). For these questions, tell us about your overall health. This information will help us better understand how you felt and how you were able to do your usual activities in (PMONTH).

1.<sup>MOS</sup> In general, would you say your health in (PMONTH) was...(READ CHOICES)

- Excellent? ..... 1  
Very good? ..... 2  
Good? ..... 3  
Fair? ..... 4  
Poor? ..... 5

2. The following questions are about activities you might have done during a typical day in (PMONTH). Did your health limit you in these activities? If so, how much? (SHOW CARD D)

<sup>MOS</sup>	Activity	Yes, limited a lot	Yes, limited a little	No, not limited at all
2a.	<i>Vigorous activities</i> , such as running, lifting heavy objects, participating in strenuous sports.	1	2	3
2b.	<i>Moderate activities</i> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	1	2	3
2c.	Lifting or carrying groceries.	1	2	3
2d.	Climbing <i>several</i> flights of stairs.	1	2	3
2e.	Climbing <i>one</i> flight of stairs.	1	2	3
2f.	Bending, kneeling, or stooping.	1	2	3
2g.	Walking <i>more than a mile</i> .	1	2	3
2h.	Walking <i>several blocks</i> .	1	2	3
2i.	Walking <i>one block</i> .	1	2	3
2j.	Bathing or dressing yourself.	1	2	3

<sup>1</sup>From MOS—SF-36

- 3.<sup>MOS</sup> During (PMONTH), did you feel downhearted and blue... (READ CHOICES) (SHOW CARD C)

All of the time? ..... 1  
Most of the time? ..... 2  
A good bit of the time? ..... 3  
Some of the time? ..... 4  
A little of the time? ..... 5  
None of the time? ..... 6

4. During (PMONTH), were you very nervous...(READ CHOICES) (SHOW CARD C)

All of the time? ..... 1  
Most of the time? ..... 2  
A good bit of the time? ..... 3  
Some of the time? ..... 4  
A little of the time? ..... 5  
None of the time? ..... 6

5. How much bodily pain did you have during (PMONTH)?

None ..... 1  
Very mild ..... 2  
Mild ..... 3  
Moderate ..... 4  
Severe ..... 5  
Very severe ..... 6

6. What was your bra size in (PMONTH)?

\_\_\_\_\_ Number      A      B      C      D      DD

7. Before (PMONTH), how satisfied were you with your appearance when dressed? Were you...(SHOW CARD E)

Very satisfied? ..... 1  
Mostly satisfied? ..... 2  
Neutral? ..... 3  
Somewhat unsatisfied? ..... 4  
Very unsatisfied? ..... 5  
REFUSED ..... 88  
DON'T KNOW/UNSURE ..... 99

8. Were you sexually active in (PMONTH)?

Yes ..... 1

No ..... 2 (SKIP TO NEXT SECTION)

8a-d. Back in (PMONTH), how much of a problem was each of the following?  
(SHOW CARD F)

	Not a problem	A little problem	A definite problem	A serious problem
8a. Lack of sexual interest.	1	2	3	4
8b. Difficulty in becoming sexually aroused.	1	2	3	4
8c. Unable to relax and enjoy sex.	1	2	3	4
8d. Difficulty in having an orgasm.	1	2	3	4

## Section IV — TREATMENT DECISIONS

INTRODUCTION: Now I would like to ask you about the time you were diagnosed with cancer in (DDATE) and about the decisions you made.

- 1.<sup>JM</sup> What happened first to make you think you might have something wrong with your breast? (DON'T READ)

Routine mammogram .....	1
Bloody discharge from nipple .....	2
Non-bloody discharge from nipple .....	3
Lump in breast discovered by patient .....	4
Lump in breast discovered by physician .....	5
Lump under arm discovered by patient .....	6
Lump under arm discovered by physician .....	7
OTHER (SPECIFY) .....	77
DON'T KNOW/UNSURE .....	99

- 2.<sup>JM</sup> What was the month and year that you first thought something was wrong?

\_\_\_\_/\_\_\_\_ (MM/YY)

- 3.<sup>JM</sup> What kind of doctor did you first go to for this problem? (IF CLINIC, PROBE FOR DOCTOR)

GP/family practice .....	1
Internist .....	2
Geriatrician .....	3
Surgeon .....	4
OB/GYN .....	5
OTHER (SPECIFY) .....	77
DON'T KNOW/UNSURE .....	99

- 3a.<sup>JM</sup> How long had you been a patient of this doctor?

\_\_\_\_ Years, \_\_\_\_ Months (00, 00 = NEW PATIENT)

3b.<sup>TM</sup> Which doctor told you that you had breast cancer?

DOCTOR/CLINIC FROM QUESTION 2 SECTION II ... 1  
Other GP/family practice ..... 2  
Other internist ..... 3  
Other geriatrician ..... 4  
OB/GYN ..... 5  
Surgeon ..... 6  
OTHER (SPECIFY) \_\_\_\_\_ 77  
DON'T KNOW/UNSURE ..... 99

4. Were you given a choice of surgeons to go to?

Yes ..... 1  
No ..... 2 (SKIP TO 4C)  
DON'T KNOW/UNSURE ..... 99

4a. What was the most important factor to you in making a choice of the surgeon?

Location ..... 1  
Availability ..... 2  
Gender of surgeon ..... 3  
Recommendation of physician ..... 4  
Recommendation by someone other than a physician ..... 5  
Surgeon's general reputation ..... 6  
Surgeon's reputation for doing a particular  
kind of breast surgery ..... 7  
OTHER (SPECIFY) \_\_\_\_\_ 77  
REFUSAL ..... 88  
DON'T KNOW/UNSURE ..... 99

4b. After your diagnosis in (DDATE), and before surgery in (SDATE), did you see any other doctors for your breast cancer?

Yes ..... 1  
No ..... 2 (SKIP TO 5)

4c. What kind of doctor or doctors did you see? (CIRCLE ALL THAT APPLY)

Internist ..... 1  
Oncologist ..... 2  
Surgeon ..... 3  
Radiation oncologist ..... 4  
Plastic surgeon ..... 5  
OTHER (SPECIFY) \_\_\_\_\_ 77  
REFUSAL ..... 88  
DON'T KNOW/UNSURE ..... 99

5. Of the doctors you saw, did any of them mention (either recommend or discuss) any of the following surgical and/or radiation treatments as options for your care?

5a.<sup>JW</sup> Surgical removal of *part* of the breast (includes biopsy that removes lump, lumpectomy, etc.): (called breast-sparing or breast-conserving surgery)

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

5b.<sup>JW</sup> Surgical removal of the *whole* breast (mastectomy)?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

5c. Surgery to check or remove lymph nodes under the arm?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

5d.<sup>JW</sup> The option of having radiation treatment after removal of a lump or part of the breast?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

6.<sup>JW</sup> Do you feel you were given a choice *about the types of surgeries or radiation treatments*?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

7. What surgical treatments did you have?

Mastectomy ..... 1  
Breast conserving surgery ..... 2  
OTHER (SPECIFY) \_\_\_\_\_ 77  
DON'T KNOW/UNSURE ..... 99

7a. Did you have (at the same time or in a separate procedure) surgery on the lymph nodes under the arm?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

8. Since (SDATE) have you received radiation treatment?

Yes ..... 1  
No ..... 2 (SKIP TO 9)  
DON'T KNOW/UNSURE ..... 99 (SKIP TO 9)

8a. On which dates?

Start: \_\_\_\_/\_\_\_\_/\_\_\_\_ (MM/YY)

End: \_\_\_\_/\_\_\_\_/\_\_\_\_ (MM/YY) 00/00 = ONGOING

9.<sup>JW</sup> Women who have a breast operation sometimes get chemotherapy which is given through a needle in the vein in the hospital, some get pills, called Nolvadex or tamoxifen, and some get both. Did any doctor talk to you about any of these drugs?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

10. Are you now taking chemotherapy that is given in the hospital by injection, or have you completed chemotherapy treatments since (SDATE)?

Yes ..... 1  
No ..... 2 (SKIP TO 11)  
DON'T KNOW/UNSURE ..... 99 (SKIP TO 11)

10a. Please tell me the date on which this treatment began.

Start: \_\_\_\_/\_\_\_\_/\_\_\_\_ (MM/YY)

10b. Please tell me the date on which it ended.

End: \_\_\_\_/\_\_\_\_/\_\_\_\_ (MM/YY) 00/00 = ONGOING

10c. Is it one drug, or more than one drug?

One drug ..... 1  
More than one drug ..... 2  
DON'T KNOW/UNSURE ..... 99



11. Was tamoxifen (Nolvadex-hormonal therapy) recommended by any of the doctors you saw?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

11a. Are you now taking tamoxifen?

Yes ..... 1  
No ..... 2 (SKIP TO 11d)  
DON'T KNOW/UNSURE ..... 99 (SKIP TO 11d)

11b. How much of the monthly cost of the tamoxifen do you pay with your own money, that is, after any payments made by any insurance that you have?

\$\_\_\_\_\_ Dollars per month (CODE UNSURE AS 999)

11c. To what extent is this cost a financial burden to you? Would you say a great deal, somewhat, or not at all?

A great deal ..... 1 (SKIP TO 11e)  
Somewhat ..... 2 (SKIP TO 11e)  
Not at all ..... 3 (SKIP TO 11e)  
DON'T KNOW/UNSURE ..... 99 (SKIP TO 11e)

11d. Did the *cost* of tamoxifen stop you from getting it?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

11e.<sup>JK</sup> Two months before your diagnosis in (DDATE), did you have any problems getting to your doctor's office appointments for check-up or going for tests?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

11f.<sup>JK</sup> After your diagnosis in (DDATE), *would you have had* problems getting transportation to a hospital or clinic for daily or weekly treatment (such as chemotherapy or radiation)?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

11g. Before your current diagnosis in (DMONTH), had you ever had any type of surgery or incision of your breast such as a biopsy?

Yes .....	1
No .....	2
DON'T KNOW/UNSURE .....	99

11h. Did any of the following people in your family ever have breast cancer?

Persons	Yes	No	Don't know
11h1. Mother or grandmothers.	1	2	99
11h2. Aunts.	1	2	99
11h3. Sisters.	1	2	99
11h4. Daughters.	1	2	99
11h5. Other relatives (SPECIFY:_____)	1	2	99

12. At the time you were diagnosed in (DMONTH) or while you were thinking about surgery, what were the most important issues or concerns that you considered? (RECORD VERBATIM)

[illegible]

13. After you were diagnosed and before the surgery you had in (SMONTH), did you consider the following issues or concerns?

Considerations	13. Considered?			14. Enter 1, 2, and 3 below
	Yes	No	Don't know	
13a. Before the surgery in (SMONTH), was wanting no treatment after the surgery a consideration?	1	2	9	
13b. Before the surgery in (SMONTH), were issues of side effects of treatment a consideration?	1	2	9	
13c. Before the surgery in (SMONTH), was wanting to live as long as possible a consideration?	1	2	9	
13d. Before the surgery in (SMONTH), was physical appearance (not wanting to lose a breast, sexual attractiveness, partner's feelings) a consideration?	1	2	9	
13e. Before the surgery in (SMONTH), was wanting to be sure that there would be the least chance of the cancer coming back a consideration?	1	2	9	
13f. Before the surgery in (SMONTH), was the inconvenience of getting to treatment a consideration?	1	2	9	
13g. Before the surgery in (SMONTH), were family preferences or concerns a consideration?	1	2	9	
13h. Before the surgery in (SMONTH), was the effect on your being able to care for yourself a consideration?	1	2	9	
13i. Before the surgery in (SMONTH), were out of pocket costs for treatments a concern for you?	1	2	9	

- 14a. I'll read a list of the things you told me were important to you in thinking about your breast cancer surgery and other treatment. Of these considerations, which was the most important (READ AGAIN IF NECESSARY). (RECORD '1')
- 14b. Which was the next most important? (RECORD '2')
- 14c. Which was the next most important? (RECORD '3')
15. How much were your decisions about the surgery and treatment you had based on what your doctor told you to do? Were they very much, somewhat or not at all based on what your doctor told you to do?

Very much .....	1
Somewhat .....	2
Not at all .....	3
DON'T KNOW/UNSURE .....	99

16. Considering your overall satisfaction with your surgery and other treatment, would you say you...(READ CHOICES) (SHOW CARD G)

Are very satisfied? .....	1
Are somewhat satisfied? .....	2
Have mixed feelings? .....	3
Are somewhat dissatisfied? .....	4
Are very dissatisfied? .....	5

17. Considering your overall health, how would you rate the impact of breast cancer on your life? Would you say it had...(READ CHOICES) (SHOW CARD H)

A major impact? .....	1
A significant impact? .....	2
Some impact? .....	3
Almost no impact? .....	4
No impact? .....	5
REFUSAL .....	88
DON'T KNOW/UNSURE .....	99

18. *Except from your doctor*, did you get any information you used for your surgery or other treatment decisions from any other source?

Yes (SPECIFY) _____	1
No .....	2
DON'T KNOW/UNSURE .....	99

19. In these next questions I will ask you about your behavior and your surgeon's behavior during your visits before your surgery in (SDATE). There are no right or wrong answers, and all answers are confidential. For each tell me how much you agree or disagree.<sup>1</sup>  
(READ STATEMENTS) (SHOW CARD I)

CL Statements	Strongly agree	Agree	Neutral	Disagree	Strongly Disagree
19a. My surgeon did not ask me about my worries about breast cancer.	1	2	3	4	5
19b. I asked my surgeon to explain breast cancer treatments and/or procedure(s) to me in greater detail.	1	2	3	4	5
19c. My surgeon encouraged me to give my opinion about my breast cancer.	1	2	3	4	5
19d. I didn't ask my surgeon a lot of questions about my breast cancer treatment options.	1	2	3	4	5

20. Considering two kinds of treatment a woman may have for breast cancer: one is to have the whole breast removed; the other is to have a lump removed and then to have radiation. Do you believe one of these treatments is more likely to keep the cancer from coming back, or are the chances the same with either treatment? (READ CHOICES)

Having the whole breast removed ..... 1  
Having a lump removed, then radiation ..... 2  
They are the same ..... 3

<sup>1</sup>Caryn E. Lerman, "Patients Perceived Involvement in Care Scale"

Now, I would like to ask you some questions about the care you received *after* your surgery on (SDATE).

21. After your surgery, did you go to...

Referral	Yes	No	Don't know
21a. Another surgeon for a second opinion?	1	2	99
21b. A radiation oncologist? (A doctor that specializes in cancer x-ray or radiation treatments)	1	2	99
21c. A medical oncologist? (A doctor that specializes in evaluating and recommending all non-surgery cancer treatments)	1	2	99
21d. A psychologist or group for support? (Emotional support, support for dealing with cancer or breast cancer)	1	2	99
21e. A physical therapist for rehabilitation? (To help with arm exercises or recovery from breast surgery)	1	2	99
21f. Another doctor or service? (SPECIFY) _____	1	2	99

21g. Did you receive skilled home health care? (PROMPT: a nurse or nurse's aide that came to your house to check your recovery after your breast cancer treatments or how you were doing during treatment)

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

21h. Did you receive homemaker services? (PROMPT: a home health aide to help you with cleaning, self-care, cooking, shopping, or other daily activities)

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

22. <sup>JRW</sup> Now I am going to ask about some other symptoms women may have after breast cancer. For each one tell me if you had it as a new problem since your surgery for breast cancer in (SDATE), and if so, whether it bothered you not at all, slightly, moderately, quite a bit, or extremely. Since your surgery in (SDATE), have you had...

FOR EACH 'YES' RESPONSE, ASK: Did that bother you not at all, slightly, moderately, quite a bit, or extremely? (SHOW CARD J)

Condition	CIRCLE ONE FOR EACH ITEM		FOR EACH ITEM, CIRCLE ONE ONLY IF PATIENT ANSWERS YES				
	No	Yes	Not at All	Slightly	Moderately	Quite a bit	Extremely
22a. Loss of arm movement on the side of surgery (since SDATE)?	1	2	1	2	3	4	5
22b. Change in weight (since SDATE)?	1	2	1	2	3	4	5
22c. Change in appetite (since SDATE)?	1	2	1	2	3	4	5
22d. Vaginal problems, including discharge, bleeding, drying, itch or irritation, or pain during sexual intercourse (since SDATE)?	1	2	1	2	3	4	5
22e. Breast soreness or pain (since SDATE)?	1	2	1	2	3	4	5
22f. Hot flashes or night sweats (since SDATE)?	1	2	1	2	3	4	5
22g. Scars that don't heal (since SDATE)?	1	2	1	2	3	4	5
22h. Mouth sores, skin redness, or blistering (since SDATE)?	1	2	1	2	3	4	5
22i. Difficulty sleeping (since SDATE)?	1	2	1	2	3	4	5
22j. Hair loss (since SDATE)?	1	2	1	2	3	4	5

(CONTINUED ON NEXT PAGE)

(CONTINUED FROM PREVIOUS PAGE)

Condition	CIRCLE ONE FOR EACH ITEM		FOR EACH ITEM, CIRCLE ONE ONLY IF PATIENT ANSWERS YES				
	No	Yes	Not at All	Slightly	Moderately	Quite a bit	Extremely
22k. Upset stomach (since SDATE)?	1	2	1	2	3	4	5
22l. Vision problems (since SDATE)?	1	2	1	2	3	4	5
22m. Unhappiness with the appearance of your body (since SDATE)?	1	2	1	2	3	4	5

23. Now I will read a number of statements which describe people's reactions to having cancer. Please tell me for each statement how much it applies to your feelings regarding your disease and treatment. The choices are: definitely does not apply to me, does not apply to me, may or may not apply, applies to me, and definitely applies to me. (SHOW CARD K)

Statement	Definitely does <i>not</i> apply to me	Does <i>not</i> apply to me	May or may not apply to me	Applies to me	Definitely applies to me
23a. I am determined to beat this disease.	1	2	3	4	5
23b. I feel like giving up.	1	2	3	4	5
23c. I feel that life is hopeless.	1	2	3	4	5
23d. I see my illness as a challenge.	1	2	3	4	5
23e. I try to fight the illness.	1	2	3	4	5
23f. I am very optimistic.	1	2	3	4	5
23g. I feel completely at a loss.	1	2	3	4	5
23h. I can't handle it.	1	2	3	4	5
23i. I feel there is nothing I can do to help myself.	1	2	3	4	5

(CONTINUED ON NEXT PAGE)



(CONTINUED FROM PREVIOUS PAGE)

Statement	Definitely does <i>not</i> apply to me	Does <i>not</i> apply to me	May or may not apply to me	Applies to me	Definitely applies to me
23j. I think it is the end of the world.	1	2	3	4	5
23k. I make a positive effort not to think about my illness.	1	2	3	4	5
23l. Not thinking about it helps me cope.	1	2	3	4	5
23m. I deliberately push all thoughts of cancer out of my mind.	1	2	3	4	5
23n. I can't cope.	1	2	3	4	5
23o. I am not very hopeful about the future.	1	2	3	4	5
23p. I distract myself when thoughts about my illness come into my head.	1	2	3	4	5
23q. I am upset about having cancer.	1	2	3	4	5
23r. It is a devastating feeling.	1	2	3	4	5
23s. I've had a good life, what's left is bonus.	1	2	3	4	5
23t. I've put myself in the hands of god.	1	2	3	4	5
23u. Since my cancer diagnosis, I now realize how precious life is, and I'm making the most of it.	1	2	3	4	5
23v. I feel very angry about what has happened to me.	1	2	3	4	5
23w. I suffer great anxiety about it.	1	2	3	4	5
23x. I am a little frightened.	1	2	3	4	5
23y. I count my blessings.	1	2	3	4	5
23z. At the moment I take one day at a time.	1	2	3	4	5
23aa. I worry about the cancer returning or getting worse.	1	2	3	4	5
23bb. I am apprehensive.	1	2	3	4	5
23cc. I have difficulty in believing that this has happened to me.	1	2	3	4	5

24. How much is spirituality and/or religion a source of strength and comfort to you?  
(SHOW CARD L)

None ..... 1  
A little bit ..... 2  
Somewhat ..... 3  
A great deal ..... 4  
REFUSAL ..... 88  
DON'T KNOW/UNSURE ..... 99

25. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what's on your mind)?

\_\_\_\_\_ Number

26. Have you participated in any other breast cancer research studies either for treatment or by being interviewed? (ATTACH LIST)

Yes ..... 1  
No ..... 2 (SKIP TO NEXT SECTION)

- 26a. What is the name of the study?

\_\_\_\_\_

- 26b. When did you participate in that study?

Start: \_\_\_\_/\_\_\_\_/\_\_\_\_ (MM/DD/YY)

End: \_\_\_\_/\_\_\_\_/\_\_\_\_ (MM/DD/YY)

00/00/00 = ONGOING

## Section V — HEALTH STATUS

Now I'd like to ask about your health *at present*.

1.<sup>MOS</sup> In general, would you say your health *now* is...

- Excellent? ..... 1
- Very Good? ..... 2
- Good? ..... 3
- Fair? ..... 4
- Poor? ..... 5

2.<sup>MOS</sup> The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? (SHOW CARD D)

Activity	Yes, limited a lot	Yes, limited a little	No, not limited at all
2a. <i>Vigorous activities</i> , such as running, lifting heavy objects, participating in strenuous sports.	1	2	3
2b. <i>Moderate activities</i> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	1	2	3
2c. Lifting or carrying groceries.	1	2	3
2d. Climbing <i>several</i> flights of stairs.	1	2	3
2e. Climbing <i>one</i> flight of stairs.	1	2	3
2f. Bending, kneeling, or stooping.	1	2	3
2g. Walking <i>more than a mile</i> .	1	2	3
2h. Walking <i>several blocks</i> .	1	2	3
2i. Walking <i>one block</i> .	1	2	3
2j. Bathing or dressing yourself.	1	2	3

- 3.<sup>MOS</sup> During the *past four weeks* have you had any of the following problems with your work or other regular daily activities *as a result of your physical health*?

Activities	Yes	No	Don't know
3a. Cut down on the <i>amount of time</i> you spent on work or other activities?	1	2	99
3b. <i>Accomplished less</i> than you would like?	1	2	99
3c. Were limited in the <i>kind</i> of work or other activities?	1	2	99
3d. Had <i>difficulty</i> performing work or other activities? (For example, it took extra effort)	1	2	99

- 4.<sup>RY</sup> How *bothered* are you by any changes in your ability to perform your regular daily activities? (SHOW CARD J)

Not at all ..... 1  
Slightly ..... 2  
Moderately ..... 3  
Quite a bit ..... 4  
Extremely ..... 5  
Not applicable ..... 6

- 5.<sup>MOS</sup> During the past four weeks have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

Activities	Yes	No	Don't know
5a. Cut down on the <i>amount of time</i> you spent on work or other activities?	1	2	99
5b. <i>Accomplished less</i> than you would like?	1	2	99
5c. Didn't do work or other activities as <i>carefully</i> as usual?	1	2	99

6.<sup>RY</sup> How bothered are you by depression or anxiety? (SHOW CARD J)

Not at all ..... 1  
Slightly ..... 2  
Moderately ..... 3  
Quite a bit ..... 4  
Extremely ..... 5  
Not applicable ..... 6

7.<sup>MOS</sup> During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (SHOW CARD J)

Not at all ..... 1  
Slightly ..... 2  
Moderately ..... 3  
Quite a bit ..... 4  
Extremely ..... 5  
Not applicable ..... 6

8.<sup>MOS</sup> How much bodily pain have you had during the past four weeks? (SHOW CARD N)

None ..... 1  
Very mild ..... 2  
Mild ..... 3  
Moderate ..... 4  
Severe ..... 5  
Very severe ..... 6

9.<sup>RY</sup> How bothered are you by bodily pain? (SHOW CARD M)

Not at all ..... 1  
Slightly ..... 2  
Moderately ..... 3  
Quite a bit ..... 4  
Extremely ..... 5  
Not applicable ..... 6

10.<sup>MOS</sup> During the past four weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (SHOW CARD M)

Not at all ..... 1  
Slightly ..... 2  
Moderately ..... 3  
Quite a bit ..... 4  
Extremely ..... 5  
Not applicable ..... 6

These questions are about how you feel and how things have been with you during the *past four weeks*. For each question, please give the one answer that comes closest to the way you feel. The answer choices are all of the time, most of the time, a good bit of the time, some of the time, a little of the time, and none of the time. (SHOW CARD C)

11.<sup>MOS</sup> How much of the time during the past four weeks...

Questions	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
11a. Did you feel full of pep?	1	2	3	4	5	6
11b. Have you been a very nervous person?	1	2	3	4	5	6
11c. Have you felt so down in the dumps nothing could cheer you up?	1	2	3	4	5	6
11d. Have you felt calm and peaceful?	1	2	3	4	5	6
11e. Did you have a lot of energy?	1	2	3	4	5	6
11f. Have you felt downhearted and blue?	1	2	3	4	5	6
11g. Did you feel worn out?	1	2	3	4	5	6
11h. Have you been a happy person?	1	2	3	4	5	6
11i. Did you feel tired?	1	2	3	4	5	6
11j. Has your health limited your social activities (like visiting with friends or close relatives?)	1	2	3	4	5	6

12. Please choose the answer that best describes how *true or false* each of the following statements is for you. (SHOW CARD O)

Statements	Definitely true	Mostly true	Not sure	Mostly untrue	Definitely untrue
12a. I seem to get sick a little easier than other people.	1	2	3	4	5
12b. I am as healthy as anybody I know.	1	2	3	4	5
12c. I expect my health to get worse.	1	2	3	4	5
12d. My health is excellent.	1	2	3	4	5

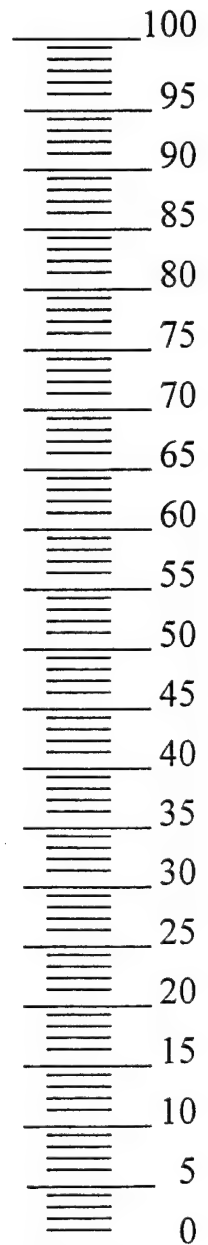
## Preferences

13. To help us understand how good or bad your health is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked by 100, and death by 0.

Now I would like you to indicate on this scale how good or how bad your own overall health is *today*, in your opinion, considering all your medical conditions. Please do this by drawing a line from the box to whichever point on the scale indicates how good or bad your current health is. (SHOW CARD P; RECORD NUMBER)

### BEST IMAGINABLE HEALTH STATE

Your own  
health  
state *today*



DEATH

\_\_\_\_\_ Number



## Section VI — UTILITIES AND COPING STYLES<sup>1</sup>

INTRODUCTION: This set of questions asks about your day to day health during the *past four weeks*. Some of these questions may not apply to you, but it is important that we ask the same questions of everyone. For some of the questions, I want you to tell me which statement *most closely describes* how you felt.

1.<sup>HUI</sup> Are you able to see well enough *without* glasses or contact lenses to read the newspaper?

Yes ..... 1 (SKIP TO 2)  
No ..... 2

1a.<sup>HUI</sup> Which of the following best describes your usual ability to see well enough to read the newspaper? Are you...(READ CHOICES) (SHOW CARD Q)

Able to see well enough, *but with* glasses  
or contact lenses? ..... 1  
Unable to see well enough, *even with* glasses  
or contact lenses? ..... 2  
Unable to see at all? ..... 3

2.<sup>HUI</sup> Are you able to see well enough *without* glasses or contact lenses to recognize a friend on the other side of the street?

Yes ..... 1 (SKIP TO 3)  
No ..... 2

2a.<sup>HUI</sup> Which *one* of the following best describes your usual ability during the past four weeks to see well enough to recognize a friend on the other side of the street?  
Would you say you...(READ CHOICES) (SHOW CARD R)

Can see well enough with glasses or  
contact lenses? ..... 1  
Cannot see well enough even with glasses  
or contact lenses? ..... 2  
Cannot see at all? ..... 3

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<sup>1</sup>15Q HUI, McMaster University, Torrance et al, with permission

3.<sup>HUI</sup> Are you able to hear what is said in a group conversation with at least three other people *without* a hearing aid?

Yes ..... 1 (SKIP TO 4)  
No ..... 2

3a.<sup>HUI</sup> Which *one* of the following best describes your usual ability during the past four weeks to hear what is said in a group conversation with at least three other people? Would you say you...(READ CHOICES) (SHOW CARD S)

Can hear what is said with a hearing aid? ..... 1  
Cannot hear what is said even with a hearing aid? ..... 2  
Cannot hear what is said, but don't wear a hearing aid? ... 3  
Cannot hear at all? ..... 4

4.<sup>HUI</sup> Are you able to hear what is said in a conversation with one other person in a quiet room *without* a hearing aid?

Yes ..... 1 (SKIP TO 5)  
No ..... 2

4a.<sup>HUI</sup> Which *one* of the following best describes your usual ability during the past four weeks to hear what is said in a conversation with one other person in a quiet room? Would you say you...(READ CHOICES) (SHOW CARD S)

Can hear what is said with a hearing aid? ..... 1  
Cannot hear what is said even with a hearing aid? ..... 2  
Cannot hear what is said, but don't wear a hearing aid? ... 3  
Cannot hear at all? ..... 4

5.<sup>HUI</sup> Are you able to be understood when speaking the same language with strangers?

Yes ..... 1 (SKIP TO 6)  
No ..... 2

5a.<sup>HUI</sup> Which *one* of the following best describes your usual ability during the past four weeks to be understood when speaking the same language with strangers? Would you say you are...(READ CHOICES) (SHOW CARD T)

Able to be understood partially? ..... 1  
Unable to be understood? ..... 2  
Unable to speak at all? ..... 3

6.<sup>HUI</sup> Are you able to be understood when speaking the same language with people who know you well?

Yes ..... 1 (SKIP TO 7)  
No ..... 2

6a.<sup>HUI</sup> Which *one* of the following best describes your usual ability during the past four weeks to be understood when speaking with people who know you well? Would you say you are...(READ CHOICES) (SHOW CARD U)

Able to be understood completely? ..... 1  
Able to be understood partially? ..... 2  
Unable to be understood? ..... 3  
Unable to speak at all? ..... 4

7.<sup>HUI</sup> Which *one* of the following best describes how you usually feel? Would you say you are...(READ CHOICES) (SHOW CARD V)

Happy and interested in life? ..... 1  
Somewhat happy? ..... 2  
Somewhat unhappy? ..... 3  
Very unhappy? ..... 4  
So unhappy that life is not worthwhile? ..... 5

8.<sup>HUI</sup> Are you free of pain and discomfort?

Yes ..... 1 (SKIP TO 9)  
No ..... 2

8a.<sup>HUI</sup> Which *one* of the following best describes your usual level of pain and discomfort during the past four weeks? Would you say you...(READ CHOICES) (SHOW CARD W)

Have mild to moderate pain or discomfort  
that prevents no activities? ..... 1  
Have moderate pain or discomfort that prevents  
a few activities? ..... 2  
Have moderate to severe pain or discomfort  
that prevents some activities? ..... 3  
Have severe pain or discomfort that prevents  
most activities? ..... 4

9.<sup>HUI</sup> Are you able to walk around the neighborhood without difficulty and without walking equipment (such as a cane or walker)?

Yes ..... 1 (SKIP TO 10)  
No ..... 2

9a.<sup>HUI</sup> Which of the following best describes your usual ability during the past four weeks to walk? Would you say you are...(READ CHOICES) (SHOW CARD X)

- Able to walk around the neighborhood with difficulty, but without walking equipment or a helper? ..... 1
- Able to walk around the neighborhood with walking equipment, but without a helper? ..... 2
- Able to walk only short distances with walking equipment, and require a wheelchair to get around the neighborhood? ..... 3
- Unable to walk alone, even with walking equipment; able to walk short distances with a helper, and require a wheelchair to get around the neighborhood? ..... 4

10.<sup>HUI</sup> Do you have full use of two hands and ten fingers?

- Yes ..... 1 (SKIP TO 11)
- No ..... 2

10a.<sup>HUI</sup> Which *one* of the following best describes your usual ability during the past four weeks to use your hands and fingers? (NOTE: SPECIAL TOOLS REFER TO HOOKS FOR BUTTONING CLOTHES, TOOLS FOR OPENING JARS OR LIFTING SMALL ITEMS) Would you say you have...(READ CHOICES) (SHOW CARD Y)

- Limited use of hands or fingers, but do not require special tools or the help of another person? ..... 1
- Limited use of hands or fingers, independent with use of special tools (do not require the help of another person)? ..... 2
- Limited use of hands or fingers, require the help of another person for some tasks (not independent even with the use of special tools)? ..... 3
- Limited use of hands or fingers, require the help of another person for most tasks (not independent even with the use of special tools)? ..... 4
- Limited use of hands or fingers, require the help of another person for all tasks (not independent even with the use of special tools)? ..... 5

11.<sup>HUI</sup> Are you able to remember most things?

Yes ..... 1 (SKIP TO 12)  
No ..... 2

11a.<sup>HUI</sup> Which *one* of the following best describes your usual ability during the past four weeks to remember things? Would you say you...(READ CHOICES) (SHOW CARD Z)

Somewhat forgetful? ..... 1  
Very forgetful? ..... 2  
Unable to remember anything at all? ..... 3

12.<sup>HUI</sup> Are you able to think clearly and solve day to day problems?

Yes ..... 1 (SKIP TO 13)  
No ..... 2

12a.<sup>HUI</sup> Which *one* of the following best describes your usual ability during the past four weeks to think and solve day to day problems? Would you say you...(READ CHOICES) (SHOW CARD AA)

Have a little difficulty when trying to think  
and solve day to day problems? ..... 1  
Have some difficulty when trying to think  
and solve day to day problems? ..... 2  
Have a great deal of difficulty when trying  
to think and solve day to day problems? ..... 3  
Are unable to think or solve day to day problems? ..... 4

13.<sup>HUI</sup> Do you eat, bathe, dress and use the toilet normally?

Yes ..... 1 (SKIP TO 14)  
No ..... 2

13a.<sup>HUI</sup> Which *one* of the following best describes your ability during the past four weeks to perform these basic activities? Would you say you...(READ CHOICES) (SHOW CARD BB)

Eat, bathe, dress and use the toilet independently  
with difficulty? ..... 1  
Require mechanical equipment to eat, bathe,  
dress or use the toilet independently? ..... 2  
Require the help of another person to eat, bathe,  
dress or use the toilet? ..... 3

14.<sup>HUI</sup> Are you generally happy and free from worry?

Yes ..... 1 (SKIP TO 15)  
No ..... 2

14a.<sup>HUI</sup> Which *one* of the following best describes how you usually feel during the past four weeks? Would you say you are...(READ CHOICES) (SHOW CARD CC)

Occasionally fretful, angry, irritable, anxious  
or depressed? ..... 1  
Often fretful, angry, irritable, anxious or depressed? ..... 2  
Almost always fretful, angry, irritable, anxious  
Or depressed? ..... 3  
Extremely fretful, angry, irritable, anxious or  
depressed, usually requiring hospitalization  
or psychiatric institutional care? ..... 4

15.<sup>HUI</sup> Are you free of pain and discomfort?

Yes ..... 1 (SKIP TO 16)  
No ..... 2

15a.<sup>HUI</sup> Which *one* of the following best describes your usual level of pain during the past four weeks? Would you say you...(READ CHOICES) (SHOW CARD DD)

Have occasional pain, with discomfort relieved by  
non-prescription drugs or self-control activity  
without disruption of normal activities? ..... 1  
Have frequent pain, with discomfort relieved by oral  
medicines with occasional disruption of  
normal activities? ..... 2  
Have frequent pain, with frequent disruption of normal  
activities, and discomfort that requires  
prescription narcotics for relief? ..... 3  
Have severe pain, that is not relieved by drugs and  
constantly disrupts normal activities? ..... 4

Now I'll ask just a few more questions about your health in the last week. Please tell me if the following statement describes you.

16. On a typical day last week I spent a lot of time feeling nervous or depressed. Does that describe you?

Yes ..... 1  
No ..... 2  
DON'T KNOW/UNSURE ..... 99

17. Next I'll read four statements to you. Please consider how you felt on a typical day this past week, and choose the *one statement* that best describes you. (READ ALL FOUR) (SHOW CARD EE)

1. I am able to walk a block and carry groceries. My pain, physical health or energy do not stop me from doing my normal activities.

2. While I am able to walk a block and carry groceries, my pain, physical health or energy have made me cut down on my normal activities.

3. Although I am not able to walk a block and carry groceries, my pain, physical health or energy have not made me cut down on my normal activities.

4. I am not able to walk a block and carry groceries. My pain, physical health or energy have made me cut down on my normal activities.

Statement 1 ..... 1  
Statement 2 ..... 2 (SKIP TO 19)  
Statement 3 ..... 3  
Statement 4 ..... 4 (SKIP TO 19)  
None of the above ..... 98  
DON'T KNOW/UNSURE ..... 99

18. Now I'll read four more statements to you. Please consider how you felt, and tell me the one statement that best describes you. (SHOW CARD FF)

1. While it is not a problem now, during the last several months my physical health, pain or energy made me cut down on my normal activities.

2. In addition to not being a problem now, during the last several months my physical health, pain or energy did not make me cut down on my normal activities by much.

3. While not a problem now, there was a month or several weeks during which my physical health, pain or energy made me cut down on my normal activities.

4. In addition to not being a problem now, I've never had major physical health, pain or energy problems.

Statement 1 .....	1
Statement 2 .....	2
Statement 3 .....	3
Statement 4 .....	4
None of the above .....	98
DON'T KNOW/UNSURE .....	99



19. Now I'll read four more statements to you. Please consider how you felt, and tell me the one statement that best describes you. (SHOW CARD GG)

1. I expect to be back to normal activity within a year.

2. While I won't ever be back to my normal level of activity, I will be closer to normal activity within a year.

3. While I won't ever be back to my normal level of activity, I can get used to working around these problems.

4. I won't ever be back to my normal level of activity, and this is causing problems that I am having a hard time working around.

Statement 1 .....	1
Statement 2 .....	2
Statement 3 .....	3
Statement 4 .....	4
None of the above .....	98
DON'T KNOW/UNSURE .....	99

Thank you for taking the time to answer these questions.

TIME ENDED:

\_\_\_\_:\_\_\_\_ AM/PM

Do you have any questions for me?

\_\_\_\_\_

Your participation is very important. You will be contacted by telephone in 9 months by another interviewer to follow-up with you and see how you are doing. We'd like to send you a project newsletter if you are interested.

Yes \_\_\_\_\_ No \_\_\_\_\_

VERIFY PATIENT'S ADDRESS. GO TO CONTACT INFORMATION.

We will be asking you some questions in about 9 months, and again in 21 months. In order to make sure we can contact you, would you please give us the name, address, and telephone number of two people close to you who would always know where you were if you were not at home.

[1]        Name        \_\_\_\_\_  
             Address     \_\_\_\_\_  
                             \_\_\_\_\_  
             Telephone    \_\_\_\_\_  
             Relationship to you    \_\_\_\_\_

[2]        Name        \_\_\_\_\_  
             Address     \_\_\_\_\_  
                             \_\_\_\_\_  
             Telephone    \_\_\_\_\_  
             Relationship to you    \_\_\_\_\_

INTERVIEWER REMARKS
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1. The respondent's cooperation was:

Very good .....	1
Good .....	2
Fair .....	3
Poor .....	4

2. The overall quality of this interview is:

Unsatisfactory .....	1
Questionable .....	2
Generally reliable .....	3
High quality .....	4

3. The main reason(s) for unsatisfactory or questionable quality of information was because the respondent: (CIRCLE ALL THAT APPLY)

Did not know enough regarding the topic .....	01
Did not want to be more specific .....	02
Did not understand or speak english well .....	03
Was bored or uninterested .....	04
Became upset, depressed or angry .....	05
Had poor hearing or speech .....	06
Was confused or distracted by frequent interruptions .....	07
Was inhibited by others around her .....	08
Was embarrassed by the subject matter .....	09
Was emotionally unstable .....	10
Became physically ill .....	11
OTHER (specify) _____	77

Comment:

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## **Appendix 2**

### **Physician Survey Instrument Developed for AHCPR Grant No. HS0835<sup>1</sup>**

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<sup>1</sup>The National Physician Survey Instrument will be derived from this instrument following analysis of preliminary data.

## OPTIONS PHYSICIAN SURVEY

You have been identified by Dr. (Name(s) of the site Principal Investigators) as a doctor involved in caring for elderly women ( $\geq 65$  years) with breast cancer.

This survey is part of a large five-year multi-institution national grant project about breast cancer outcomes in the elderly. The goal of the study is to understand which treatment combinations yield the best outcomes for particular types of elderly women. **The research team has no pre-conceived idea of the most appropriate type of treatment for elderly women.**

We would appreciate your completing this short survey which should take you about 15 minutes and returning it to the project office in the enclosed envelope.

**Your responses will be confidential, and you will not be identified by name.**

If you have any questions about the project, you can contact Dr(s) (name(s) of site Principal Investigator(s)) at (phone number).

Thank you.

## Section I - DEMOGRAPHIC INFORMATION

1. Birth date \_\_\_\_/\_\_\_\_/\_\_\_\_  
(MM/DD/YY)

**FOR QUESTIONS 2-9, PLEASE MARK (X)  
ONE RESPONSE**

2. Gender

- ☐ Male  
☐ Female

3. Year of medical school graduation 19\_\_\_\_

4a. Board certification in general surgery

- ☐ Yes  
☐ No

4b. Secondary certification beyond your  
general surgery residency

- ☐ Yes  
☐ No

5. Did you do specialty training in surgical  
oncology beyond your general surgery  
residency?

- ☐ Yes  
☐ No

6. Type of practice (If you practice in more  
than one, choose the one in which you  
spend the most time):

- ☐ Private solo  
☐ Private group  
☐ HMO  
☐ Teaching hospital  
☐ Community hospital  
☐ Other (SPECIFY) \_\_\_\_\_

7. Are you affiliated with a teaching  
hospital?

- ☐ Yes  
☐ No

8. Are you affiliated with an  
NCI-designated cancer center?

- ☐ Yes  
☐ No

Please give your **BEST ESTIMATES** when answering  
the following questions:

9. What percentage of your surgical practice is breast  
cancer? \_\_\_\_\_%

10. What is the number of breast cancer patients of all  
ages you treated in 1994. \_\_\_\_\_

11. What proportion of your breast cancer patients  
treated in 1994 were:

- Less than 50 years old? \_\_\_\_\_%  
50 to 64 years old? \_\_\_\_\_%  
65 to 74 years old? \_\_\_\_\_%  
Greater than 74 years old? \_\_\_\_\_%

The next 3 questions involve only the patients in your  
practice 65 and over with T<sub>1</sub>/T<sub>2</sub> breast cancer and nodal  
status N<sub>0</sub>/N<sub>1</sub> (either clinical or pathological) seen during  
1994.

12a. What percentage received:

- Breast-conserving surgery (BCS) \_\_\_\_\_%  
Mastectomy \_\_\_\_\_%

12b. Of those that received BCS, what percentage  
received:

- RT \_\_\_\_\_%  
No RT \_\_\_\_\_%

12c. What percentage of patients received:

- Axillary dissection \_\_\_\_\_%  
No axillary dissection \_\_\_\_\_%

12d. Of those that received BCS, what percentage  
received:

- RT \_\_\_\_\_%  
No RT \_\_\_\_\_%

13. Regardless of local treatment options, what  
percentage received:

- Tamoxifen \_\_\_\_\_%  
No tamoxifen \_\_\_\_\_%

14. Regardless of local treatment options, what  
percentage received:

- (Including node-negative, positive, and nodal status  
unknown patients)  
Chemotherapy \_\_\_\_\_%  
No chemotherapy \_\_\_\_\_%

**Section II — CLINICAL SCENARIOS: THE FOLLOWING 3 SCENARIOS ASK FOR YOUR OPINIONS ABOUT TREATMENT OF HYPOTHETICAL ELDERLY PATIENTS.**

**A. Scenario 1:** A 73 year-old woman presents with a lesion seen in the upper, inner quadrant of the left breast seen on screening mammography. The mammogram was done because her neighbor in the retirement community developed breast cancer. On physical examination, no masses are palpable in the breast, and she has no adenopathy. A needle-localization biopsy is done revealing a 1.0 cm well-differentiated infiltrating ductal carcinoma. Margins of excision are negative. The tumor is ER-positive, PR-positive, diploid and with an S-phase of 2.7%. She has a long-standing history of diabetes mellitus and has been treated for foot ulcers. She lives in her own apartment in the retirement community. The management provides transportation to medical appointments.

We recognize that many factors, particularly patient preference, go into a treatment decision. However, **please answer the following questions indicating which treatment you would prefer the patient undergo.**

PLEASE MARK (X) FOR EACH QUESTION	
<p>1. Local therapy</p> <p><input type="checkbox"/> Breast conserving surgery</p> <p><input type="checkbox"/> Breast conserving surgery and radiation</p> <p><input type="checkbox"/> Mastectomy (with or without reconstruction?)</p>	
<p>2. Would you recommend surgery to evaluate the axillary nodes?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No <i>Skip to 5</i> →</p>	
<p>3. If axillary surgery is done and the nodes are negative, would you recommend:</p> <p><input type="checkbox"/> Tamoxifen</p> <p><input type="checkbox"/> Chemotherapy</p> <p><input type="checkbox"/> Both</p> <p><input type="checkbox"/> Neither</p>	
<p>4. If axillary surgery is done and the nodes are positive, would you recommend:</p> <p><input type="checkbox"/> Tamoxifen</p> <p><input type="checkbox"/> Chemotherapy</p> <p><input type="checkbox"/> Both</p> <p><input type="checkbox"/> Neither</p>	
	<p>5. If axillary surgery is <b>not</b> done, would you recommend:</p> <p><input type="checkbox"/> Tamoxifen</p> <p><input type="checkbox"/> Chemotherapy</p> <p><input type="checkbox"/> Both</p> <p><input type="checkbox"/> Neither</p>

**A. Scenario 2:** A 74 year-old widowed woman with no underlying medical problems presents with a 1.5 cm palpable mass in the sub-areolar region of the right breast. There is no nipple discharge. On examination, this subareolar mass is palpable, but there are no other masses, and there is no palpable adenopathy. Her breasts are large. The mammogram confirms the presence of the sub-areolar mass but shows no other abnormalities. True-cut core biopsy of the tumor reveals a moderately differentiated adenocarcinoma. The tumor is ER-positive, PR-negative, aneuploid and with an S-Phase of 12%.

We recognize that many factors, particularly patient preference, go into a treatment decision. However, **please answer the following questions indicating which treatment you would prefer the patient undergo.**

PLEASE MARK (X) FOR EACH QUESTION	
<p>1. Local therapy</p> <p><input type="checkbox"/> Breast conserving surgery</p> <p><input type="checkbox"/> Breast conserving surgery and radiation</p> <p><input type="checkbox"/> Mastectomy (with or without reconstruction?)</p>	
<p>2. Would you recommend surgery to evaluate the axillary nodes?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No <i>Skip to 5</i> →</p>	
<p>3. If axillary surgery is done and the nodes are negative, would you recommend:</p> <p><input type="checkbox"/> Tamoxifen</p> <p><input type="checkbox"/> Chemotherapy</p> <p><input type="checkbox"/> Both</p> <p><input type="checkbox"/> Neither</p>	
<p>4. If axillary surgery is done and the nodes are positive, would you recommend:</p> <p><input type="checkbox"/> Tamoxifen</p> <p><input type="checkbox"/> Chemotherapy</p> <p><input type="checkbox"/> Both</p> <p><input type="checkbox"/> Neither</p>	
	<p>5. If axillary surgery is <b>not</b> done, would you recommend:</p> <p><input type="checkbox"/> Tamoxifen</p> <p><input type="checkbox"/> Chemotherapy</p> <p><input type="checkbox"/> Both</p> <p><input type="checkbox"/> Neither</p>



**A. Scenario 3:** A 70 year-old married woman with no past medical history presents with a palpable mass in the upper outer quadrant of the right breast. Clinically, the axillary nodes are negative. The mammogram reveals an isolated mass. The patient undergoes an excisional biopsy that reveals a 2.5 x 2.0 x 1.0 cm moderately differentiated infiltrating ductal carcinoma with extensive intraductal carcinoma within and around the invasive component. The specimen size measures 3.5 x 2.5 x 1.5 cm and the margins are microscopically negative. The invasive tumor is ER-negative, PR-negative. The invasive tumor is aneuploid and the S-phase is 11%.

We recognize that many factors, particularly patient preference, go into a treatment decision. However, **please answer the following questions indicating which treatment you would prefer the patient undergo.**

PLEASE MARK (X) FOR EACH QUESTION	
<p>1. Local therapy</p> <p><input type="checkbox"/> Breast conserving surgery</p> <p><input type="checkbox"/> Breast conserving surgery and radiation</p> <p><input type="checkbox"/> Mastectomy (with or without reconstruction?)</p>	
<p>2. Would you recommend surgery to evaluate the axillary nodes?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No <i>Skip to 5</i> →</p>	
<p>3. If axillary surgery is done and the nodes are negative, would you recommend:</p> <p><input type="checkbox"/> Tamoxifen</p> <p><input type="checkbox"/> Chemotherapy</p> <p><input type="checkbox"/> Both</p> <p><input type="checkbox"/> Neither</p>	
<p>4. If axillary surgery is done and the nodes are positive, would you recommend:</p> <p><input type="checkbox"/> Tamoxifen</p> <p><input type="checkbox"/> Chemotherapy</p> <p><input type="checkbox"/> Both</p> <p><input type="checkbox"/> Neither</p>	<p>5. If axillary surgery is <b>not</b> done, would you recommend:</p> <p><input type="checkbox"/> Tamoxifen</p> <p><input type="checkbox"/> Chemotherapy</p> <p><input type="checkbox"/> Both</p> <p><input type="checkbox"/> Neither</p>

**Section III — TREATMENT PRIORITIES:** These next questions are about your general priorities in making treatment recommendations to elderly women ( $\geq 65$ ) with breast cancer.

The first section addresses **LOCAL TREATMENT** options. In women with localized cancer who are candidates for breast conserving surgery, **WHICH FACTORS GO INTO YOUR DECISION TO RECOMMEND A BREAST-CONSERVING APPROACH WITH OR WITHOUT RADIATION OR MASTECTOMY?** Please indicate how important each factor is to you in making recommendations to **ELDERLY WOMEN**.

MARK (X) ONE FOR EACH				
	Very Important	Important	Slightly Important	Not Important
1. 5 year survival.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Disease-free survival.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Local recurrence rates.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Cosmetic results.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Tumor size	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Axillary nodal status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6a. Clinically negative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6b. Clinically positive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Treatment side effects:				
7a. Surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7b. Radiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7c. Systemic chemotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7d. Hormonal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Patient chronological age.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Patient co-existent medical conditions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Risk of general anesthesia, or other operative morbidity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Patient's preferences.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Patient quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Costs of treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Patient's social support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Patient's convenience.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Avoiding a second surgery for local recurrence.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**PLEASE LIST THE TOP 3 FACTORS IN ORDER OF IMPORTANCE IN MAKING TREATMENT RECOMMENDATIONS:**

\_\_\_\_\_  
(1)                      (2)                      (3)